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ABSTRACT

This booklet is written for physicians, nurses, social workers, psychologists, and other health care professionals who must deal with children with a life-threatening illness. It is for health care professionals who seek to help the child live as normal a life as possible in spite of a difficult situation. In five sections, the writings and research of health care professionals who have written on this topic are reviewed and shared with the reader. Part A: Laying the Groundwork for Communication with a Child with a Life-Threatening Illness, contains discussions of parents' philosophical and emotional stance on death, and the concept of death among children in general and among seriously ill children in particular. Part B: Communication with Family Members, includes material on the family as a support system, siblings and spouses. Part C: Communication between Health Care Professionals and the School, provides guides for preparing the teacher and explores specific issues relative to school. Part D: Objections to Talking to a Seriously-Ill Child About Death, lists eight objections and provides answers to the objections. Part E: How to Talk to a Seriously-Ill Child about Death, suggests 11 highly subjective points to be discussed with a child, in an age-appropriate manner, at the child's own level of readiness. (Author/RH)

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TALKING WITH CHILDREN WITH A LIFE-THREATENING ILLNESS: A HANDBOOK FOR HEALTH CARE PROFESSIONALS

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TALKING WITH CHILDREN WITH A LIFE-THREATENING ILLNESS: A HANDBOOK FOR HEALTH CARE PROFESSIONALS

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INTRODUCTION

This booklet is written for physicians, nurses, social workers, psychologists, and other health care professionals who must deal with children with a life-threatening illness. It is for health care professionals who seek to help the child live as normal a life as possible in spite of a difficult situation.

The diagnosis that a child has a life-threatening illness comes as a staggering blow to family, friends, and school. The ability of the health care professional to help the child and family cope is critical since the child may have years of valuable life ahead. A child with a serious illness continues to achieve and develop. He or she is entitled to as healthy an environment as possible.

While each family and each child within a family is unique, and while each family's past experiences, individual personalities, economic and social standing, political and religious orientations differ, parents of seriously ill children share many common experiences and feelings, as do the children themselves, their siblings, and their teachers. We have reviewed and will share with you the writings and research of health care professionals who have written on this topic.

For all children, the family is the primary environment through which they grow into happy, and functioning adults. Parents share a portion of their child-rearing responsibilities with the educational system. The school, with its teachers, counselors, administrators, peers, rules and regulations, is the supplementary environment through which the child grows to adulthood. Because the family and the school represent the main environment in which children grow, this discussion of communication between the health care professional and the child with a life-threatening illness will take into account the child's dependence for growth upon family and school. The health care setting for the child with a life-threatening illness such as cancer or leukemia, cystic fibrosis, congenital heart disease, nephrosis, and other potentially fatal diseases, takes on special significance in the life of these children, and in its own way represents an extension of the family and school.

This discussion will be divided into the following sections:

PART A: Laying the Groundwork for Communication with a Child with a Life-Threatening Illness;

PART B: Communication with Family Members;

PART C: Communication between Health Care Professionals and the School;

PART D: Objections to Talking to a Seriously Ill Child about Death;

PART E: How to Talk to a Seriously Ill Child about Death.

NOTE: When we use the terms *mother, father,* or *parent* in this booklet, we are not necessarily referring to the biological parent. We are referring to the persons who consistently and over time have been performing the mothering and/or fathering role. In some cases, the parenting person may be the child's aunt, grandmother, or stepfather. Thus, the *family,* as defined in this booklet, consists of those persons who are living together in the same household, and who are functioning as parents and children.

PART A: LAYING THE GROUNDWORK FOR COMMUNICATION WITH A CHILD WITH A LIFE-THREATENING ILLNESS

How should a child with a potentially fatal illness be told about his prognosis and treatment regimen? It is our belief that it is better to address the issue of the seriousness of the child's illness from the time of diagnosis.[35,36,37] In this way, energy that would be wasted in maintaining a deceit can be applied to the very real problem of living with a life-threatening illness.

With medical changes in recent years increasing the lifespan of many children with life-threatening illnesses, the health care professional tends to respond to the child's questions early in the course of the illness with a reality-based hope and optimism. Parents also are encouraged to keep their own hopes alive.[8,22,24,49] However, the potential threat to life is always present, and one cannot hide the truth indefinitely. Even when not told, the child will soon conclude that he or she has a very serious illness and suspect that the disease is potentially fatal.[6,34] While hope of cure should be maintained, it is unrealistic to think that a child over four or five years of age can be kept unaware indefinitely of the potential fatality of the illness.[40,41]

The task of telling a child about his diagnosis, treatment regimen, and potentially shortened lifespan is not an easy one. Certainly this task cannot be accomplished bluntly, casually, brutally, or in a single session. While it is important to communicate openly and honestly with children, the issues surrounding the mechanisms for communicating are complex and very much related to the child's level of development. This section of the handbook will lay the groundwork for communication with a child about the illness. When one writes a "How to . . ." treatise, statements inevitably become prescriptive and subjective. The authors make no apologies for either. What is presented here is an approach to communication with the child based on a decade of both rigorous research and clinical practice in this area. The prerequisites discussed in this section apply throughout all sections of this handbook. Understanding the prerequisites is essential before meaningful communication can take place with the child about the illness.

By using the term "prerequisite" we do not mean that no communication is to take place at all until the five conditions are present. A physician and members of his or her team who strive in their pediatric service for an atmosphere of honesty and openness regarding the treatment of a life-threatening illness must, by necessity, be honest from the point of diagnosis onward. Our position is that the questions and concerns raised by family members as the disease progresses demand a concerted effort on the part of the health care professional to fulfill the five conditions before a level of conversation can take place that is understandable by parent and child, and ultimately beneficial to both. It is this meaningful level of conversation to which our five prerequisites apply.

The health care professional can best lay the groundwork for a meaningful conversation with the child by understanding:

The Parents' Philosophical Stance on Death;
The Parents' Emotional Stance on Death;
The Child's Age, Experience, and Level of Development;
Family Coping Strategies; and
The Child's Affinity for Process over Content.

THE PARENTS' PHILOSOPHICAL STANCE ON DEATH

An essential prerequisite to a meaningful communication with the child about his or her illness is a basic understanding of the family's view of life.[19,28] It is especially important, when dealing with an issue so basic to the human condition as a potential threat to life, that one understand both the force of the basic parenting demand and the critical role of the family as the prime emotional and intellectual environment for the child.[39] A family resides within a larger social and cultural context. A family has a manner of facing life, a manner of placing meaning to the mystery of life and death that may be long-standing within the traditions of past generations,[48] or of brief standing within the context of a new-found cosmology, or even lacking altogether for want of ever having had the need or courage to face the issue previously.

The social context of the family's private cosmology/theology/philosophy of life and death is the environment from which the child will draw his or her own meaning and strength. It is necessary that the professional come to terms with his or her

own view of the purpose of life and death; it is also critical that, as much as possible, the professional attempt to understand the parents' philosophy of life. Should a discrepancy appear between the professional's view and the parents' view, it is not advisable for the professional to attempt to change the parents' beliefs at this time. To attempt to replace the parental cosmology at so critical a time as the crisis point of diagnosis of a potentially life-threatening illness, can lead to failure to make the most of the remaining years of life of the child, and most especially to a failure in ultimate adaptation of the parents and surviving siblings after the death of the child.[36,39] In a recent study it was demonstrated that firm commitment to a family-consistent and time-honored view of the place of death in life was critical to the ultimate adaptive efforts of the surviving family members.[43]

In brief, professionals who talk to the child must keep in mind that families differ in what they bring to the illness in terms of philosophical stance on the place of death in life. The professional must guide the family in its efforts to tap its own basic strengths, rather than attempt at this critical time to pursue a course of radical change in the parental views.

THE PARENTS' EMOTIONAL STANCE ON DEATH

As important as the parental cosmology is to the family's ultimate adaptive efforts, even more important is how well the family has incorporated that stance.[12] It is not so much what death is that concerns most of us; it is rather how we feel about death.[10,18,20] When one is dealing with the parents of a child who has been diagnosed with a life-threatening illness, it is critical to be patient, to allow time to become aware of, and help the parents become aware of, both their general and specific attitudes and emotional responses toward the concept of death. Has the family experienced death before? Was it the death of a grandparent? An uncle or aunt? A close friend or neighbor? What was the mother's reaction? What was the father's reaction? Did they grieve at the same pace or in different manners? Did they share their feelings of grief with each other and with other family members, or did they suffer in isolation and silence. Did they involve the children? At what age? Knowledge of the general and specific history of the family's emotional approach to

the concept of death is the second prerequisite to talking to the child about his own potentially life-threatening illness.

THE CHILD'S AGE, EXPERIENCE, AND LEVEL OF DEVELOPMENT

A third prerequisite to a meaningful communication with a child about his illness is a basic understanding of developmental levels in the growth of the child's thought processes, notably those surrounding the concepts of life and death. There are many books and articles which speak to this issue.[9,13,16,18,42] Although it is difficult to do justice to so complex a topic in so brief a space, we will address this issue at this point in an overview fashion, so that we can place the issue in proper perspective. We will address the topic in two phases: (1) The Child's Concept of Death, and (2) The Seriously Ill Child's Concept (or understanding) of Death.

The Child's Concept of Death

Concepts of death are age-related in children and differ with intellectual ability and development.[4,42] It is generally believed that during the first two years of life, there is no understanding of death as such, but fear of separation from protecting, comforting persons is present in its most terrifying intensity. While death is not yet a fact of life for the child going on three, anxiety about separation remains all pervasive. Some time between the ages of three and five, most children first comprehend the fact of death as something that happens to others. At this time, the concept of death is still vague. It is associated with sleep and the absence of light or movement and is not yet thought of as permanent. In contrast to toddlers, most children of this age are able to withstand and understand short separations. They often respond more spontaneously and with less anxiety to questions about death than do older children. They are also curious about dead animals and flowers. However, children between three and five typically deny death as a final reality. They believe death is accidental and they themselves will not die.

Attitudes and concepts of children do not change abruptly at any given age, but evolve gradually and with wide individual variation. This is true whether one is talking about the concept of

time, the concept of space, or the concept of death. From approximately the age of six onward, the child seems gradually to be accommodating himself or herself to the proposition that death is final, inevitable, universal and personal. Many six and seven year olds suspect that their parents will die some day, and that they too may die, but only in the very distant future. Children in these early school years show a strong tendency to personify death. Many children, at their initial awareness and discovery of death, are horrified, confused and angered. Although some recent authors feel that because of exposure a child in the present day and age is coming to grips with the concept of death at a younger age,[14] most still agree that the child under ten has not yet attained a well-developed understanding of death.[4,42] As children approach adolescence, they are equipped with the intellectual tools necessary to understand time, space, life and death in a logical manner. At about the age of ten or eleven the fact of the universality and the permanence of death becomes understandable.

What we have discussed to this point is the normal development of the ability to conceptualize death in children. A speeding up of the process occurs when the child is faced with death at an early age, often at a level preceding the child's ability to conceptualize it.[6,7,34,51]

The Seriously Ill Child's Concept of Death

It is important when speaking to children with a life-threatening illness about the concept of death to understand differences in ability to conceptualize because of the child's age and level of development. At the same time, it must be remembered that a child who is experiencing the day-to-day effects of a life-threatening illness and the often drastic changes in the emotional climate that accompany this disease may become aware of his own impending demise at a much younger age than his healthy peers and at a level that often the child himself cannot conceptualize. Recent studies of six-to-ten-year-old children with life-threatening illnesses reveal that, despite efforts by parents and medical personnel to keep the child from becoming aware of the prognosis, he somehow picks up a sense that the illness is no ordinary illness. The fear of abandonment and separation, characteristic of the younger child, has added to it a fear of

bodily harm and injury and possible awareness of his own impending death, or, at the very least, the awareness at a level preceding his ability to conceptualize it, that something very serious is happening. The awareness of his own impending death becomes stronger as the child nears death.[7,40,41]

FAMILY COPING STRATEGIES

A fourth prerequisite to communication with a child about the potentially fatal nature of his disease is an understanding of the family's usual manner of dealing with crises. An understanding of the past, present and possibly changing coping modes of the various family members as individuals and of the family as a social group is essential if a professional is to tap the family's own resource pool. Individuals have different levels of stress tolerance, different levels of ability to deal with stress, and different histories of success and failure in overcoming stress.[32,33] What works for the professional may not work at all for the family, especially when the family is in the middle of sustaining the burden of a life-threatening diagnosis in their child. The very diagnosis itself can shift the family's central survival skills into a newer mode. At this stage in the family's development, the individual members need a professional who is willing to understand and help them strengthen their usual mode of coping with crises, help them grow into facing this particular crisis, give them the tolerance and patience they will need to make the transition, and remain non-critical in the process. This is not a time for imposition. It is a time for support.

THE CHILD'S AFFINITY FOR PROCESS OVER CONTENT

The fifth and final prerequisite for communicating with a child about the potential threat to his own life is a basic understanding of how a child works. It is especially true of children that actions speak louder than words. Children pay more attention to what you *do* and to *how* you say something *(process)* than to *what* you say *(content)*. Long before an infant develops the ability to verbalize, he can pick up subtle and not-so-subtle cues of tension, anger, or happiness from his mother. As a child grows, he remains attuned to non-verbal cues in the environment.[29] Children are dependent on the adults around them to help explain what they are feeling. In a communicating family,

the parents try to explain to the child what he is feeling, and soothe the child's expressed concerns. However, when the parents reach an area that may be of some emotional distress for them, they may fall short in their attempts at explanation. When children do not find an acceptable explanation to fit what they sense, they let their imaginations take over. The children may assume that they did something wrong, and that's why mommy and daddy won't explain things fully to them. The children may feel that the medical intrusions are punishments for wrong doing. Unless someone explains to the children, at their level, what is happening, the children may have to deal with imagined fears, distresses, and concerns that are much more disturbing and difficult to deal with than the actual facts.

Children are attuned to non-verbal cues in their environment. An understanding of this concept is a prerequisite to meaningful communication with the child.

PART B: COMMUNICATION WITH FAMILY MEMBERS

The seriously ill child over four or five years of age does not always verbally express his fears about impending death. However, these fears and anxieties are real, painful, and related to the seriousness of the illness that the child is experiencing. These anxieties are present in the child whether or not the family wishes the child to know his diagnosis. Children eventually become aware of the seriousness of their illness.

How do these children deal with their knowledge? How do the families react? While the health care professional must attempt to understand the particular family structure and environment under which an individual child must live and grow, and while each family's adaptive capabilities and coping styles may differ, there are common patterns of communication among family members that are peculiar to the families of children with a life-threatening illness. It is these common elements which this section of the booklet will address.

If it is true that children as young as four or five are aware of the serious nature of their illnesses, what do they do with this knowledge and awareness? Do they talk openly with their

families about the prognosis, or do they live in silence with the knowledge? What roles do the families play in the children wishing to talk or not to talk about the illnesses? Studies of family communication patterns about the issue of serious illness in children show that the level of family communication about the illness, as expressed in the mother's judgment of communication, relates to coping strategies in the child.[39] Families in which levels of communication about the illness are high are those families in which the children: (1) exhibit a nondefensive personal posture, (2) express a consistently close relationship with the parents, and (3) express a basic satisfaction with self. The parental level of willingness to discuss the illness is most important in the child's decision about what to do with the knowledge. Children who have the personal desire and parental permission to discuss their illness openly within the family structure are in the best position to receive the type of support they need.[36]

Circumstances of pain, reactions to medication and treatment, and the death of other children from the illness, all play a role in children's increasing awareness of the severity of their illnesses. Some professionals encourage denial in order for the children to maintain mental as well as physical comfort, and to a point, some brief denial may appear helpful.[1,17,25] However, children, siblings, and parents are best served in the long run by being encouraged to bring into the open their anxieties about the illness and its possible consequences.[7,11,42]

In a series of interviews conducted with families whose children had died from a life-threatening illness after the age of six, the most frequently discussed issue was the extent to which the family had communicated with the child about the possible terminal effects of the illness.[4] About one-half of the families interviewed felt they had talked freely and openly with their children about their impending deaths. None of the parents who had spoken openly with their child felt that too much had been said; on the contrary, these parents felt that a higher level of closeness was achieved with the child than might have occurred otherwise. The memory of the open discussions and exchange of family values before the child's death had sustained the families during the mourning process. The siblings in the open group reported having had time to say goodbye to their dying brother or sister, to resolve old quarrels, and to help their dying sibling in his or her own efforts to say goodbye as well.

The families whose children had died without open discussion of the illness or of the imminent death usually wished they had spoken more openly with their child. These parents reported feelings of incompleteness and nonresolution. Those siblings who reported unresolved feelings regretted not having been forewarned or not having had time to say goodbye and settle differences before the child's death.

Further studies are needed as to what to say and when, taking into consideration the severity of the illness, parental and sibling readiness, and age levels of the children. Nevertheless, studies to date point to the fact that children understand that their illnesses are serious, and encouraging children to talk about the illness usually has beneficial short- and long-term effects on all family members, including the life-threatened child.

Though desirable, open communication in all families in all circumstances is not always possible. Although open communication is generally of supportive value to the sick child, a forced openness too soon can be destructive for some specific families. Some parents are initially unable to communicate openly under the stress of a seriously ill child and exhibit maladaptive behavior, being inaccessible, withdrawn and remote.[36] The goal in working with these parents should be to help them become aware of the false sense of equilibrium that comes from excessive denial of the problem and the harm such denial can cause the sick child. Temporary use of denial of a serious illness can allow the family time to pull together adaptive resources. However, in dealing with such a family, care should be taken to prevent the "temporary" state of denial from becoming self-perpetuating.

We have found that the life-threatened child chooses whether or not to talk about his illness based on his experiences within the family regarding openness of communication about illness. A child may choose silence because he senses that his family forbids discussion of the illness or the child may communicate openly because the family reinforces openness. Either choice represents a different style of coping. The choice of silence can lead to excessive denial and avoidance, and a feeling of rejection and isolation. The child may feel that he has been left alone to work out his problems. In contrast, open discussion, stemming from the sincere attempts of family members to communicate concern and support, encourages expression of feelings. Open expressions of the child's fears relative to the illness can lead to

mutual support among family members, helping the child achieve a balanced adaptive equilibrium.

THE FAMILY AS A SUPPORT SYSTEM

When open communication begins in a family, complex sets of feelings emerge. Openness increases expressed levels of anxiety within the family and commits family members, as well as others who must deal with the family members, to a confrontation with the severity of the illness. The open family may be torn apart by the confrontation or it may come through the adaptive struggle with members having grown closer together, having gained an ability to struggle valiantly in future life conflicts, and having achieved a level of confidence, strength, and reevaluation of basic life commitments that will make for a more effective and fulfilled life.

People deal with crises, well or poorly, using coping mechanisms.[25,26] Even escape through suicide or mental illness represents a mechanism for coping. In families coping with a life-threatening illness, it is important to place the coping patterns of each member within the context of the family's primary role as support environment for its members. If a family loses its common objectives, reduces cooperation among members, if members do not reciprocate services (most notably in the sexual roles of the spouses) or fail to coordinate functions or lack consensus of emotional attitudes, then, no matter how well an individual member adapts to a life-threatening diagnosis, the family itself has failed in its primary function of social support of its members. The result is family disorganization and possible disintegration if the situation continues for long. While individual family members may cope effectively and well without family support, effective coping is the exception in families in which communication is minimal and disorganization is high.

In the family of a child with a life-threatening illness, parents are often so overwhelmed by the illness that they do not prepare for ordinary events; for example, a child diagnosed with a life-threatening illness at two years of age can at five begin to have problems in school simply because his mother did not engage in the ordinary preparatory steps for school. An event such as the child's beginning school is such a minor event to the mother in comparison to the illness itself, that she does not prepare the child to enter school. If the child had not developed a

life-threatening illness three years earlier, the mother would have placed into perspective the child's needs for preparation for school, with its accompanying social demands from the child's school-aged peers. What happens is a basic failure in family communication: the mother's attempts at coping with her child's illness, though successful regarding the illness, leave the mother with little energy to deal with the child's new problem, entry into school. The mother, while coping with the illness, is not giving her child the type of support he needs to cope with a non-disease task. Similarly, other ordinary life transitions of children, such as entry into junior high school, pubescence, or transfer to a new city, can become crises because the family, overwhelmed by a life-threatening diagnosis in the child, has frozen efforts at growth. It is as if the family unit were saying to itself: "If only we can hold it all together and keep from falling apart, we'll make it." Such a mode of coping with the illness precludes the type of openness to growth and change that is necessary as the children move through various developmental crises on their way to adulthood. Such a family fails to devote the necessary energy to help the child in his time of greatest non-disease need.

SIBLINGS

What has been stated about the child with a life-threatening illness also holds for the siblings. The siblings of a child with a life-threatening illness are often neglected by the parents, not because sibling needs are not important, but because their needs take on a lesser importance relative to the diagnosis of a life-threatening illness. Siblings in the families of children with a life-threatening illness often face alone the developmental tasks necessary to achieve adulthood. Attempts by the siblings to seek help from parents often meet with a plea to be mature and generous, and to respect the needs of the ill child. Even the mentally strong and healthy sibling cannot be expected to go through life's transitional stages without support from parents who have "burned out" from strategies used in coping with their ill child's diagnosis.

SPOUSES

What has been said about the child with a life-threatening illness and his siblings also holds for the parents. The parents, occasionally in unison but more often in their own separate ways,

expend their energies dealing with the illness. Usually, remaining life tasks, such as career, finances, and sexual life, take on a lowered significance. When a parent's needs are not met within the family unit, the parent may turn outside the family to fulfill the needs. Separation and divorce can result from this activity.

In summary, a family spends a large amount of energy in attempting to keep itself from becoming disorganized and disintegrated under the overwhelming threat to the life of one of its members. In the process of dealing with a life-threatening illness, the family finds itself with little energy left to fulfill its primary function as a support system to each of its members. Individual members may find their own special needs unmet. What must occur is that family members communicate their needs at a level that can be effectively understood by others in the family. Unless this communication occurs and individual family members are able to continue to receive support for their own needs from the family system, those individuals will be forced to look elsewhere for the support the family no longer gives.

The goal of working with the families of children with a life-threatening illness is to help them strengthen their own adaptive capabilities and coping styles. The health care professional treating the child must take into account the family structure and environment.[49] To help family members use the support systems they will need during the remaining months or years of their child's life and after the child's death, is the goal for which the professional dedicated to the care of the total child must strive.

PART C: COMMUNICATION BETWEEN HEALTH CARE PROFESSIONALS AND THE SCHOOL

A major part of normal growth and development for all children involves school. For a child with a life-threatening illness, a return to school represents a continuation of life, hope for the future, and an attempt to reestablish equilibruim — an equilibruim that does not deny the fact of the illness, but encompasses the new reality base of a potential threat to life. School personnel play a crucial role in determining whether or not the child with a potentially life-threatening illness can live a normal life, since so much of the child's day is centered around school. Teachers, counselors, school nurses, and administrators must be prepared to deal with this added responsibility.[44]

The physician, either directly or through a school-trained educational liaison who is an integral member of the health care team, can best help the child by opening and keeping open lines of communication with the school.

A return to school for a child with a life-threatening illness involves personal interaction, typically with one teacher at the elementary school level, five or more at the secondary level, plus school nurses, counselors, administrators and peers. Each of these individuals brings to the child their own philosophy of life, attitudes toward death, and understanding of the illness. Furthermore, each school often has an identifiable attitude toward working with any child with a medical problem in the regular classroom. It is, therefore, imperative to prepare significant school personnel for the reentry of the patient-student. The school needs: first, accurate medical information specific to the particular student/patient; second, an understanding of the psychosocial implications of the illness as it relates to the child and his family; and finally a referral source, someone who is part of the health care team, who can answer questions as they arise. When this is done, the school, the environment in which the child spends many hours each day, will promote rather than interfere with the child's efforts to cope with his school life within the context of the illness. If the school is not adequately prepared, the

environment in which the child spends many hours each day may interfere with the child's efforts to cope with his school life within the context of the illness.

PREPARING THE TEACHER

Health care professionals associated with the medical management of potentially life-threatening illnesses in children realize that the children are living longer than in the past. However, professionals outside the medical environment, such as school teachers, frequently equate life-threatening illnesses with death. Since such illnesses no longer always result in death, this attitude must be addressed if teachers are to be adequately prepared to handle children with life-threatening illnesses in the classroom. Just as each member of the medical staff has his own philosophical position on death, so too does each member of the school staff. A specific teacher's philosophy of death may differ from that of his colleagues, and from that of the parents of the child. The presence of a possibly life-threatened child in the classroom causes reflection and concern among the school staff. For some teachers this may be a personally unsettling experience. It is necessary to assist teachers in understanding their own attitudes and emotional responses toward the concept of death. The teacher must also gain an appreciation of the child's understanding of death and realize that each family has its own manner of dealing with such a crisis. It is important to help teachers realize that all children are very sensitive to non-verbal cues in their environment. If the teacher is uneasy about having a child with a potentially life-threatening illness in the classroom, the child will sense this at a non-verbal level, and there may be negative consequences in his academic and social performance. The child will also sense a warm, caring, supportive attitude on the part of the teacher. The teacher must realize that he is working not only with a child, but also with a family in crisis.

It is also important to help teachers understand that a child with a serious illness can continue to achieve and develop, and may have years of valuable life ahead. Hope is essential in dealing with these students. Unlike denial, hope does not interfere with healthy adjustment and is entirely compatible with an acceptance of reality.[25] When caregivers lose the hope for cure, development can be hampered. Some caregivers may expect a child to die and, therefore, not do what is needed to help the

child develop. This attitude, termed "psychological euthanasia,"[49] may serve to protect caregivers, but is devastating to the child in the classroom. It is imperative, then, that teachers be helped to understand that a child with a life-threatening illness is a living, growing, developing child valiantly trying to learn in spite of a difficult situation.

SPECIFIC ISSUES RELATIVE TO SCHOOL

Many children with a potentially life-threatening illness have difficulties in school for a variety of reasons. Hair loss, weight loss or gain, and reduced stamina are the most obvious and most often discussed. Yet, many children who have an understanding of the reasons for these obvious physical changes and have been well prepared by both the medical staff and their parents can explain to their classmates the reasons for the physical changes, and thereby gain the understanding and support of their peers. The more directly school-related problems can be more devastating than the disease-related problems simply because the former are more subtle and easily overlooked; for example, a child with a serious illness may either have or develop a reading problem. Teachers who view the child as living despite the illness see the need for referring the child for appropriate diagnostic evaluation and remediation. Teachers who view the child as dying do not refer, and the child goes from grade to grade carrying the burden, not only of the illness, but also of a worsening reading difficulty.

Attendance at school may be a problem because of frequent clinic visits and occasional hospitalizations. Many teachers are very cooperative and flexible, and allow the child to make up work. Others, especially at the secondary level, do not. The adolescent's need for privacy, coupled with a teacher's need for an excuse for absence, can often conflict. This especially becomes a problem when the child's teachers do not accept the fact of the illness, or the adolescent refuses to tell the teacher what he or she really has. Bridging this communication gap is critical, and can best be done by a professional trained both in the school and in the hospital environments.

A well prepared teacher is a valuable link in the total care of the child. A teacher who is prepared to deal with the family in crisis, as well as with the child, is in a position to communicate with parents in a way health care professionals might not be. For

example: many children are found to have the illness before entering school. Beginning school is a significant step for all children and their parents. If the child is successful in entering school, the parents feel rewarded in their efforts to promote normal growth and development. If a child has problems in school, parents may link the problems to some other cause. If the child has an illness, they may blame the illness for non-illness-related difficulties. A well prepared teacher will point out to these parents that many other children have difficulties at the beginning of school as well, and that the difficulties are not those only of children with a serious illness. This support of the parents at a critical transition time by a competent teacher helps the child.

The transition from elementary to junior high school is stressful for all students, not merely for the student with a life-threatening illness. School related activities are particularly significant for the adolescent patient. Diseases and their treatment may prevent or impede successful development of autonomy, acquisition of consistent body image and sex roles, establishment of peer relations, and the adoption of future oriented social and intellectual preparation. It is important to allow an adolescent to maximize his sense of control, and the school is one area where the adolescent patient can do this. It is essential that school personnel understand the particular illness and its related consequences as they apply to the adolescent.

Since children with life-threatening illnesses are living longer and seeking a normal life by attending school, communication with the school becomes, not a luxury, but a vital and essential element in the total care of the child. Everyone involved benefits from expanded communication with the child's school: the child is happier in school; teachers are more comfortable in their roles; the parents are content that the child is safe, productive, and functioning like other children his age; and the physician obtains a more complete picture of the child. Teachers and other school personnel play a significant role in the life of the child. Given adequate preparation, information, and support, they are an essential and valuable link in the total care of the child.

PART D: OBJECTIONS TO TALKING TO A SERIOUSLY-ILL CHILD ABOUT DEATH

Despite all that has been said about the importance of honesty and open patterns of communication within the family, between the physician and the family members, and with the school personnel, health care professionals may still have objections to talking to a child about the seriousness of his or her illness. There are several common objections to talking to a child with a life-threatening illness about his possible impending death.[37] In the following paragraphs the eight most common objections will be discussed.

Objection One. Children do not understand the meaning of death, let alone their own possible impending death. We should not add to their burden by telling them things that they may not even imagine.

Response One. Children do know about death, at ages much younger than previously had been imagined. Talking to the child about the possibility of early death does not teach the child anything new; instead, the child is learning that he may speak freely of his concerns. In the past, the diagnosis of a fatal illness in children was typically followed very shortly by death. Many physicians at that time felt that the child could and should be protected from knowledge of impending death. Medical progress has increased the longevity of children with life-threatening illnesses, and brought a change of attitude toward communicating with the child about the illness. Many professionals dealing with such children now advocate an open and honest approach with the children in the manner suggested above.[6,7,34,42]

Objection Two. If it is true that one is confirming the child's suspicions by discussing the possibility of death, then it would seem clear that even if the child suspects, he is better off not being told outright.

Response Two. The fear of the unknown is worse than the fear of the known, especially for the child. The child whose suspicions remain unconfirmed becomes isolated, depressed and confused.[34,38,39]

Objection Three. Communicating with the child will not help him; it will only bring up additional problems. The adults in the child's world have the strength necessary to shoulder the burden and it is not fair to force the child to share such a burden at so young an age.

Response Three. Communication reduces feelings of isolation, depression and confusion.[39] Giving the child an opportunity to express negative and positive concerns allows that child to have a healthier self-concept and the ability to live as normal and full a life as possible within the context of the illness.

Objection Four. Communication can hurt the siblings and parents because after the child dies they will have to live with the knowledge that they failed to protect the child from the burden of awareness.

Response Four. In interviews conducted with families after the death of a child, the parents who showed the healthiest and most advanced level of adaptation to life without their child were those who reported having spent the years of diagnosis and illness communicating openly with their child.[43]

Objection Five. If a parent talks about a potentially shortened lifespan with his own child where other parents and children may overhear, it may prove harmful to them. You must be sensitive to the needs of others.

Response Five. This is true. You must be sensitive. However, other parents can also be helped by an atmosphere in which they can talk freely about their feelings. Talking about their concerns can help reduce tension and will allow them to be prepared for untoward eventualities.[42,47]

Objection Six. Not all families can endure or sustain open communication. You must be sensitive to the needs, abilities and levels of readiness of specific families.

Response Six. The above objection is true. While families cannot be categorized into types, we have found over the years that families differ in their approaches to communication and support. For example, we have found at least three different approaches of families to issues of communication and support: (1) supportive, (2) quasi-supportive, and (3) non-communicative.[35,36] Some families, because of previous experiences with

crises, and basic views of life, not only talk openly about life's concerns, but allow freedom of open expression of positive and negative feelings. Such families are supportive of the needs of individual members. Families we have termed quasi-supportive may talk openly about the illness, but do not allow the child and other family members to talk openly about feelings. In such families, there is often a non-malicious, well-intentioned resistance to open communication, suggesting that levels of support may be less than genuine. Some families are non-communicative, do not mention the word cancer, and do not allow conversation either about death or about any other crisis in the family structure. Such families appear to need support toward greater levels of communication. It is critical to help these families communicate more effectively, while taking into account their lack of experience in dealing openly with such critical issues.

Objection Seven. If the medically-trained members of the health care team take time to discuss with a family the psychosocial issues surrounding the prognosis, then a new plateau of communication has begun with that family. The professional no longer will be able to deal solely with the medical aspect of the illness; he or she will be forced to deal with problems at the more time-consuming psychosocial level. Physicians and nurses cannot deal with all of their patients in this way; besides, they are not trained to handle such problems.

Response Seven. While it is true that many physicians and nurses are not trained to handle such problems, it is difficult for them to treat children without becoming involved with the psychosocial problems of the family. Medical decisions for diagnostic or therapeutic measures are increasingly conjoint decisions made between physicians and parents. As more open communication occurs between physicians and families, physicians find themselves becoming involved in psychosocial areas of concern. While they may not have received formal training in dealing with psychosocial problems, physicians and nurses who take the time to deal with such concerns often find that they can be of help to the families. Of equal importance, many physicians and nurses find an immeasurable reward and support for themselves that comes from having done just that little more for the families. However, if the medically-trained members of the health care team are

unable because of constraints of time, lack of training, or unwillingness to provide this support, then a person with psychological expertise should be assigned to the health care team to deal with such issues.[1]

Objection Eight. Health care professionals cannot continue to deal at intense personal levels on a daily basis without themselves being affected. The danger of "burn-out" is always present.

Response Eight. This is a serious problem for physicians and non-medical professionals in the health care setting who deal directly with the psychosocial issues surrounding the diagnosis of a potentially life-threatening illness in children. A professional in the health care setting — physician, nurse, psychologist, social worker, or minister — who continues to respond to the needs of families, parents, children, siblings, and fellow staff members will himself need support to avoid "burn-out."[3,31,50] There are several responses to the problem: (1) Remove oneself from the feeling level; deal with children as objects to be studied and cured. (2) Give totally and completely to each family that demands it; burn out early, leave the profession. (3) Deal with "burn-out" before it occurs. Obviously, the third response is the most desirable. This can be accomplished by (a) communicating at a personal level with medical peers about the problems that occur in working with families at this close a level, and (b) learning to "get away." Getting away often means taking long weekends off, days off, vacations, or learning to reduce levels of stress by a variety of self-relaxation techniques.[32,33]

As we noted above, there are five prerequisites to talking to a child about a potentially shortened lifespan. Critical factors include being aware of the child's level of development, familial patterns and coping strategies, the family's attitudes toward death, and the professional's awareness of his own philosophic and emotional position toward death in his life. At least an initial attempt at self-awareness on the part of the health care professional and a resolution of objections to talking to the child are essential before the professional can undertake meaningful communication with a child about his or her prognosis.

PART E: HOW TO TALK TO A SERIOUSLY-ILL CHILD ABOUT DEATH

How do you talk to children about their own possible early death? Keeping in mind the internal attitudes discussed above, and formulating the conversations within the context of the specific and personal environment of the child, the health care professional may find the following points helpful in talking to children about their own possible death. Some of the points may be raised when the child expresses initial concern over his or her own possible death from the disease; the first eight points, for example, can be raised in the context of life and living, noting that the child may have months and even years of valuable life ahead. Other points, especially numbers 9 to 11, should be reserved for the child whose disease course has brought him very close to the actual point of death. In all cases, it is important to remain aware of the child's level of concern, to couch the conversations in the child's language, and to raise points in a tactful, process-oriented manner.[37]

The following are suggested as points to be discussed with a child, in an age-appropriate manner, at the child's own level of readiness:

(1) Death, like birth, is a part of the natural order of things. It happens sooner for some, later for others. The child's disease may shorten his life span, but we do not know how much. It is good to keep hope alive.

(2) Death has social significance. We have special feelings for the other persons we share our lives with, as they do for us.

(3) Death is a separation on both sides. Not only does the child who dies lose his family, siblings and friends, but the parents lose their child as well.

(4) The loss is never complete. The deceased lives on in some way. (Here the specific cosmological stance of the family is critical; some feel that the child will live on in spirit; others that the child will have passed on a legacy of the meaning of life to friends; and others that the child will live on in both body and soul for eternity.)

(5) The child will not be alone at death and after death. (What the child is looking for is parental presence and support throughout, both during the death process and after death. It is important to reassure these children that they will not be alone at death, and the the parents will remain with them even after death. This point is essential to the child, and of necessity should be phrased within the context of the parent's cosmological stance, as with point 4.)

(6) At the time of death, people need to know that they have done all they could do with their lives. This is a universal human concern that is shared by children as well as adults. Even children who die at an early age can live fulfilled, happy lives and make lasting contributions to the human condition. Young children can touch the minds and hearts of those they deal with at school, in the hospital, and at home, in a manner that will live on in others' memories. If the child's life and death can help modify some other person's attitudes in a manner that helps improve the human condition, that child will have contributed to humanity and will have led an effective life.

(7) The child needs to be reassured that it's all right to cry and feel sad. The feelings of sadness will come and go. The child will often feel sad when he thinks about his illness. It's all right for the child to feel angry and resentful, too. The feelings of anger will come and go. Finally, the child needs to be reassured that it's all right not to want to talk to anyone about death or illness for a while. Sometimes it is best for the child to tell others bluntly that he does not want to talk about it right now. When the child is ready to talk about death, the adults in his life will be ready to listen and support. (This had better be true.)

(8) The child needs to be reassured that silence is acceptable. It is not necessary for the child to express how he feels in words. Sometimes it's all right just to sit there and not have to talk, and if what the child says when he wants to talk sounds confused or silly, that's all right too. Adults don't always know what to say either.

(9) When death finally comes, it will not hurt. There may be pain in the period leading up to death, but the doctors will do what is necessary to reduce the pain to a minimum. Death itself won't hurt. After death the pain will never return. (Children are very concerned with having the pain finally end. It is important to reassure them that it will finally end.)

(10) When someone we love dies, it is important for us to be able to say goodbye. People have a social custom of saying their last goodbyes together. When they do this, they usually talk over what has happened and cry together. Sometimes, the person who is going to die will want to say goodbye to his friends. This is a very good thing to do. It makes the person feel better and makes his friends, brothers and sisters, and parents feel better, too. Afterwards, the child's mother and father will want to have their friends over, too, to talk about the child and how much they love him. Sometimes the adults do this in the privacy of their homes; sometimes they do it in church. These goodbye group-happenings are called funerals. People should not be afraid of funerals. They are very important for parents, brothers, sisters, and friends.

(11) Adults sometimes don't know very much about death either. If parents talk with a doctor and cry afterwards, or if they talk about their child's illness and become teary-eyed, it's because they love their child and don't want to lose him. However, if a child has to die, his parents, family and friends will remember the happy times, and the child's memory will live on in mind and spirit. (See numbers 4 and 5 above.) Parents are happy knowing that their children have been happy.

The above points are highly subjective and are listed here because they have proved helpful in conversations with children. They should be applied with caution and judgment, at the child's own bidding, and at a level comfortable for the child. The most important of all the suggestions to be kept in mind throughout any conversation with a child is that a child is more process-oriented than content-oriented. Children pay less attention to what is said, and more to the concern with which it is said. The content of a communication with a child is important; yet, all

sorts of things can be said and all sorts of "mistakes" can be made, and the child will overlook them if the manner in which they are said is in tune with the child. However, no matter how well rehearsed and "correct" the content is, if the manner is lacking or not in tune with the child, the conversation often will become unidirectional. It is important to remember the time frame and level of readiness of the child. What is said early in the period of illness in response to the child's questions will be more in a context of hope for a lengthy survival. The last three points, 9-11, are more appropriate at a later point in the illness, and most appropriate as the child nears the point of death.

CONCLUSIONS

The health care setting for the child with a potentially life-threatening illness, such as cancer or leukemia, cystic fibrosis, congenital heart disease, nephrosis, and other potentially fatal diseases is three-fold: the hospital, the family, and the school. All three elements must be addressed if effective communication is to take place. To expect to communicate with a child about diagnosis, treatment, and prognosis without taking into account the child's primary growth environments is to fail to communicate with that child.

How do you talk to a child about his own possible early death? — with great difficulty, with great concern, with care for the child, and with a heavy price on your own emotions and feelings. But the reward for your efforts will be a child who realizes that he or she is not alone in facing the most difficult task all of us ultimately must face, the fact of our own death. The failure to make the effort can only lead to isolation, loneliness, and ultimate despair in the child. Making the effort, giving the child the social support and understanding needed, has as its reward the fullest gifts that can be shared by anyone: love, understanding, and shared concern for each of our roles in the basic human condition.

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